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Social, Cultural and Systematic Frustrations Motivating the Formation of a DIY Hearing Loss Hacking Community

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ABSTRACT

Research on attitudes to assistive technology (AT) has shown both the positive and negative impact of these technologies on quality of life. Building on this research, we examine the sociocultural and technological frustrations with hearing loss (HL) technologies that motivate personal approaches to solving these issues. Drawing on meet-up observations and contextual interview data, we detail participants’ experiences of and attitudes towards hearing AT that influences hacking hearing loss. Hearing AT is misunderstood as a solution to the impairment, influencing one-to-one interactions, cultural norms, and systematic frustrations. Participants’ exasperation with the slow development of top-down solutions has led some members to design and develop their own personalised solutions. Beyond capturing a segment of the growing DIY health and wellbeing phenomenon, our findings extend beyond implications for design to present recommendations for the hearing loss industry, policy makers, and importantly, for researchers engaging with grassroots DIY health movements.

CCS CONCEPTS

• **Human centered computing** → **Human computer interaction (HCI)**; *Field Studies*; Empirical studies in HCI; • **Human centered computing** → **Collaborative and social computing**; • **Human centered computing** → **Accessibility**; Empirical studies in accessibility.

KEYWORDS

DIY; health; assistive technology; hearing loss; social; hacking.

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1 INTRODUCTION

Currently approximately 360 million people in the world live with disabling hearing loss (HL) [73]. The two main types of HL are sensorineural, causing distortion of sounds, and conductive, causing sounds to be quieter [3]. Much research has been geared towards older adults [13,26,49]. However, there are also a significant number of younger individuals who are diagnosed with hearing loss [50]. For example, 8.5% of young adults aged 20-29 years in the US exhibit hearing loss [1].

There is currently no cure for hearing loss, but assistive technologies (AT) can help to improve the hearing experience, such as hearing aids and cochlear implants. Beyond these worn ATs, there are other carried devices such as the ‘Roger Pen’ [75], which is a microphone that improves speech understanding in noisy environments and over distance. Many public environments are also increasingly adopting the ‘T-loop’ system, which is an AT that picks up magnetic signals and subsequently amplifies sound directly through the miniature wireless receiver in hearing aids and cochlear implants [76]. There are several open source medical apps for smartphones and tablets that are efficient alternatives to mono-functional and expensive AT [75]. Other wearable devices for hearing loss are available, such as AUDIS which provides awareness of environmental sounds through a smartwatch that vibrates whenever a sound is detected [47]. There have been moves to make hearing AT more accessible to a range of users, and in fact the designers of AUDIS engaged users in the design and evaluation of the smartwatch. However, our participants found that not all ATs are appropriate for all types of hearing loss and there are still issues with their design [44,64], which has motivated them to hack and make their own ATs.

Recently, there has also been an emphasis on ‘do-it-yourself’ (DIY) health and AT technologies in HCI [52], that has close links to research on people adapting and adopting their own personal solutions [6,29]. DIY health

and wellbeing is growing, and individuals are creating technology solutions sometimes at a faster rate than manufacturers. For example, DIY diabetes groups such as Nightscout have designed technologies that can upload blood glucose levels to smartphones for remote monitoring, which was not previously possible with available consumer technologies [38,39]. Another concept that is becoming increasingly popular in the HCI community is healthcare ‘hacking,’ which involves a meetup of individuals from various backgrounds to produce innovative solutions to health and wellbeing problems [52]. While there has been research into DIY technologies in the diabetes and prosthetics community [11,38,39,52,56], little work has been focused on HL.

In this paper, we engaged with and observed the start of a hearing loss meet-up group inspired by the DIY diabetes movement and explicitly interested in ‘hacking hearing loss’. We explored participants’ frustrations about hearing loss and the personal solutions that were created to combat them. We present the results of our investigation, discussing how healthcare systems, manufacturers, and researchers might support DIY health groups.

2 RELATED WORK

2.1 Sociocultural Impacts of Hearing Loss and AT

The most fundamental aspects of communication can be seriously impaired by hearing loss. For individuals over the age of 60, HL has been shown to strongly correlate with depression, and if left untreated, can contribute to health decline [18]. Similarly, research has shown that hearing loss can negatively impact social interactions between children and their peers, as they exhibit deficits such as verbally based learning difficulties [16]. However, most research on the negative social impact of HL concerns older adults [18,25,36] or the young [16], even though the impact on hearing loss across all ages is significant [2].

Work in Science and Technology Studies on perceptions about cochlear implants has highlighted differences between the everyday use of these technologies and the theoretical and ethical framing around technologies that visibly ‘fix’ a disability [9], and there is controversy around treating deafness as a disability [8]. This is important for framing this work, as the difference between HL and deafness is significant. Whilst there is controversy around the social impacts of technologies that treat deafness as a disability, there has

been work showing positive impacts on the social and communicative aspects of older people’s lives who adopt hearing aids for hearing loss impairments [12].

While hearing ATs can be used to facilitate communication and the hearing experiences of the hard of hearing, social factors can demotivate individuals from using AT. In 1985, Danhaur et. al coined the term “*the hearing aid effect*” with regards to observed negative attitudes towards people who wear hearing aids [19]. However, observers of the use of visible AT can be influenced in their perception of its use based on their knowledge of the person. For example, it has been found that observers consider head-mounted displays such as Google Glass as more socially acceptable when used to support someone with known disability [59].

These perceptions impact visible use, and it has been found that the more public aspects of interaction with devices are a key source of discomfort and aversion to the adoption of on-body interactive technologies [20]. For instance, in a study of asthma electronic monitoring devices that monitors inhaler use, it was found that participants were wary about the attention that the use of such devices drew [32]. These studies demonstrate how social factors can impede the use of ATs, including those that can improve the hearing capabilities of individuals with hearing loss.

2.2 User Attitudes Towards Assistive Technologies

Several studies have investigated user attitudes towards their ATs. A study of the experience of parents using Nightscout with their children who have Type 1 diabetes revealed that while Nightscout allowed closer monitoring of extremely low or high glucose levels, it also resulted in a sense of extreme monitoring and a loss of self-control [38]. Another study of adults using Type 1 diabetes devices showed that their use, adoption and user experience is impacted by both personality and social circumstances [55]. Such research provides insight into the nuances behind adopting and using ATs, which may not be as clear cut as simply deciding to use or not to use an AT.

Additionally, sociocultural influences such as social stigma and judgment due to the visibility of ATs often leads users to modify, hide or abandon their AT [60]. Appearance [7,44], vanity [22], self-consciousness [33] and stigma [21,25] have been raised as reasons impacting the adoption, attainment, and use of hearing loss technologies. A systematic review of literature on non-use of hearing aids also showed psycho/social issues,

situations, and device factors were reasons people did not use them despite being fitted for them [44]. Ravneberg describes the design of hearing loss technologies as neglecting the importance of quality of life, which is associated with their aesthetics [64]. A study of satisfaction levels of the elderly with eyeglasses, dentures, and hearing aids, the latter came out on the bottom [67].

It was found that while ATs can empower individuals with HL and provide a high level of autonomy when communicating with hearing individuals, they can also lead to breaks in conversations that generate discomfort for the user by emphasizing their disability and dependency on technology for communication [34]. Such findings demonstrate the variety of factors that influence the use of AT and provides a background on why people might be motivated to engage in designing their own HL solutions.

2.3 DIY and Hacking Assistive Technologies

To overcome frustrations and the sociocultural consequences that can arise from the use of ATs, users have turned to DIY and hacking to create fast-paced personalised solutions to their specific frustrations [28,63]. What is now being described as a flourishing scene of DIY makers, is turning visions of tangible and ubiquitous computing into products [41,74]. Often, these activities take place in settings referred to as hackerspaces, which enable communities and groups to have a physical space to bring people together in implementing ideas [41,72]. Individuals often take part in these activities for purposes other than financial gain [40] and can share these designs online and opensource [11]. DIY and hacking should not simply be perceived as a hobbyist or leisure practice, but as a professionalizing field functioning in parallel to research and industry labs [41].

Currently, there are a group of makers in the prosthetics [65] and diabetes communities developing their own bespoke solutions to health and wellbeing issues [14,38,39]. These makers range from producing low-fidelity products such as luggage tags and stickers [11], medium fidelity products as 3D printed prosthetic parts [11], and high fidelity movements such as #WeAreNotWaiting that utilize their technical expertise to create and release software/hardware solutions sometimes faster than manufacturers [51].

In terms of hearing loss AT, there is less research concerning DIY making and hacking, but at least one HCI study has investigated hearing technology customization [61]. While sociocultural issues such as unwanted

attention or stigma can lead to the abandonment of hearing ATs, it has also led some hearing AT users to customize their devices to be more aesthetically pleasing [61]. They have formed online communities where customization tools and techniques are shared among hearing AT users, which provides both encouragement and support for hearing AT use. It was found that users customize their devices for self-expression and to demonstrate their sense of fashion [61]. While such research into DIY customization of hearing ATs is valuable for informing the design of more customizable hearing ATs, it does not explore DIY solutions for other frustrations that can arise within the hearing loss community.

2.4 Towards Hacking Hearing Loss

There has been a sustained effort in the field of human computer interaction to design assistive technologies for hearing loss. For instance, a mobile cloud platform for helping individuals to raise awareness of their potential hearing loss [37], dynamic captioning to improve their experience in understanding video content [31], and 'VisAural' which converts audible signals into visual cues via LED signals [27]. However, while these devices may improve the hearing and communication experience for the hard of hearing, there is little HCI research on factors that may influence people to adapt and hack HL technologies.

The studies reviewed suggest that while ATs are available to impact the impairment for individuals with HL, both positive and negative consequences of their use have been identified. Additionally, studies on the use of DIY and hacking in creating solutions to frustrations with ATs are a potentially viable solution to user concerns. However, there is little work on investigating whether DIY solutions can apply to hearing AT users and what might motivate them to hack hearing loss.

3 METHODOLOGY

A pragmatic situated approach [69] was taken for this exploratory research. After giving a talk on DIY research at a London wearable tech meet-up, the first author was informed about the intention to start a hacking group around hearing loss motivated by the DIY diabetes movement by the last author. The group agreed to be part of this research and university ethics approval was sought to carry out observations and interviews. We were invited to observe the first meetings of a meet-up group, which was started to discuss hearing loss and possible DIY

solutions. We then further engaged members in one-to-one interviews. Although we provided meeting space, the meet-ups were started and attended by people in London on their own volition. We call them ‘participants’ as they consented to this research study, however researchers did not lead discussions or engage meaningfully during the meet-ups other than to consent the attendees, set up audio/video equipment, take notes and provide refreshments. We engaged reflexively in the analysis because our presence may have influenced the discussions and therefore the findings.

3.1 Participants, Data Collection and Procedure

Participants signed up to a hearing hacks meet-up group online and through a mailing list. Thirteen participants (nine male) in their 20s, 30s and 40s attended the meet ups (MU1, MU2, MU3, and MU4), with motivations including personal hearing loss, relationships with someone with hearing loss, or careers related to hearing loss (see Table 1). Five participants were interviewed (CI) in public places, such as cafes and restaurants. Most were London residents, and others lived in nearby areas. Three participants were at that time employed at tech companies or completing a technical PhD. All other participants were moderately tech literate.

Table 1. Participants with Hearing Loss status (HL), Meet-Up Attendance (MU), and Contextual Interview Attendance (CI)

	HL	MU1	MU2	MU3	MU4	CI	Notes
P1 (m,30s)	y	x	x	x	x	x	works in tech
P2 (m,30s)	y	x	x		x	x	works in tech
P3 (f,30s)	y		x	x	x	x	
P4 (f,20s)	n	x	x	x	x		speech therapist
P5 (f,20s)	n	x	x	x		x	partner
P6 (m,20s)	y	x					
P7 (m,30s)	n	x					audiologist
P8 (m,30s)	y	x					
P9 (m,30s)	y		x			x	
P10 (m,30s)	n				x		tech PhD
P11 (m,40s)	y				x		
P12 (f,40s)	y				x		
P13 (m,30s)	y				x		

At the meet-ups, data was collected through observation notes by at least one researcher and through audio/video recording the conversations around hearing loss and hearing technology. Photos were also taken of AT brought to the meetings that participants showed each other. The first meet-up was 1hr 27min, the second was 2hr 36min, the third was 3hr 30min, and the forth was 2hr 40min. As agreed in the second meet-up among attendees,

some participants brought ideas for hearing loss solutions to the third meet-up. In this meet up, participants attempted to make some of their solutions tangible through materials provided by the researchers, such as LED lights, coloured strings and moldable plastic.

The second data collection method was contextual interviews (CI) [3] with five participants in public social settings such as cafés of their own choosing, and one on video Skype. Interview durations ranged from 40 mins to 1hr 10 mins. A semi-structured interview script addressing key topics on the user experience of AT and experience creating personal solutions was used for each participant. This was carried out whilst simultaneously probing responses and tailoring certain questions to particular participants [31]. Interviewees were compensated with a £15 voucher.

Before the meet-up or interview began, an email describing our study was sent to the HL mailing list used to start and organize the meet-ups. A printed information sheet explaining the study was handed to each participant as they arrived at the Meet-ups or emailed to CI participants, and verbal or written informed consent was obtained.

3.2 Data Analysis

All audio and video recordings of the meet-ups and interviews were transcribed verbatim and imported onto atlas.ti for iterative team-based thematic analysis [10]. Notes were shared between researchers as a basis for consensus and understanding, but did not directly inform the atlas.ti analysis. The analysis began with open coding of all transcripts to identify salient concepts, and then re-coding specific sections. Transcripts were then re-read to ensure that all codes were necessary and whether codes could be separated or combined. Once the codes were sufficiently representative of the salient concepts found in the transcripts, they were arranged under higher level and sub-themes that were ordered to form coherent progressions of participants’ thoughts. A final review of all themes and sub-themes was conducted to ensure that all themes contained relevant sub-themes, and whether every theme had representative quotes from the codes.

4 FRUSTRATIONS MOTIVATING HACKING

The findings of the analysis and integrated discussion are presented below with the identification of how social, cultural, and systematic frustrations with HL motivated and shaped personal DIY hearing loss solutions.

4.1 Hearing Technology Use in One-to-One Interactions

We found that social factors stemming from one-to-one interactions impacted participants' use of hearing technology, particularly misconceptions, conversation quality and topic, and personal relationships.

4.1.1 Misconceptions About Hearing Loss. One of the most common frustrations was the lack of common understanding about *"what it is actually like"* (P5, MU1) to experience hearing loss. It was shared that people *"don't really get it and to them I look normal"* (P3, MU2), and those with functional hearing have trouble understanding the complexity of hearing loss: *"people think you either have sound, or you don't have sound, they don't realise there's a distortion and a lack of clarity"* (P3, MU2).

This lack of understanding could subsequently lead to poor or awkward interactions. Asking to repeat was common among participants, often with the result of a slower rather than a louder response: *"you know, I was paying attention, I could work out what she was saying if she just said it louder"* (P2, CI). Participants mentioned strategies that could help facilitate conversations, such as actively explaining how best to communicate with them. However, knowledge of such strategies was not universal. P5 discussed how her grandmother lacked the ability to communicate her needs, which impacted conversations with family: *"She was just like 'oh just speak up a bit' and there are so many other things that could be done that she had no idea about"* (P5, MU2).

4.1.2 Conversation Flow, Repetition and Pretending with HL. Having hearing loss made participants' aware of their interactions with others. Participants were commonly self-conscious about asking people to repeat themselves for fear of seeming *"rude"* (P3, MU2) or feeling like they were demanding too much of the person they were conversing with: *"it kind of feels like really demanding to ask somebody to change the way they are for you"* (P3, MU2).

There is a flow to conversing with *"a difference between a functional communication and a good flowing fluid one"* and *"missing stuff or being slow to respond to stuff can drag you over that line"* (P2, CI). Asking people to repeat themselves can change the rhythm of conversations causing frustration: *"if somebody's in the flow and you're interrupting them... that's a big deal"* (P2, MU2). An in-the-moment processing skill to rapidly decide which pieces of verbal information are important to hear ('Managing Resource Availability' [23]), was described by P12 as

"tiring": "decision making all the time. Deciding which are the important things that you need to go back to, and which of the ones to let go" (P12, MU4)

Participants were also reluctant to interrupt the conversational flow *"because people do get pissed off eventually they go 'oohh nevermind'"* (P3, MU4). Participants described situations where they were unwilling to interrupt this flow, so they end up pretending to hear: *"I was just going 'uh-huh uh-huh uh-huh, oh! Mh, right, hm, interesting' without knowing a single word"* (P11, MU4). Many participants adopted the strategy of pretending to hear, but this could have longer-term costs when interacting with people without HL. Pretending reduced opportunities to explain specific HL needs: *"If we pretend once, people think we hear, [...] and we never get the chance to say, 'okay can you speak to me a little bit differently'"* (P1, MU4).

4.1.3 Hearing Loss as a Topic of Conversation. Participants spent a lot of time explaining their hearing loss, which then became the main topic of many conversations (with the danger of it becoming the *"only topic of conversation"* (P3, MU2)). P1's hearing loss facilitated education among his friends, and also facilitated self-reflection on his own experiences: *"they start to notice that you are wearing hearing aids and they ask me questions [...] that was a good thing because it made me just, you know, face the problem"* (P1, MU1). This 'teaching' often involved helping others adapt how they spoke. For instance, P1 used a chart at home with his girlfriend without HL to help reinforce the methods she could use that helped P1 to hear.

Participants also mentioned changing the way in which they talked about their assistive technologies because *"even calling them hearing aids, or wearable devices, there's a subtle difference. I hate saying hearing aids"* (P12, MU4). Some participants started seeing their use of assistive hearing technologies as *"being part cyborg"* (P2, MU4) or *"like spy kid"* (P12, MU4). They also started describing their hearing loss in more creative ways to get around preconceptions surrounding hearing loss [9, 10, 35], such as at a technology conference: *"I say 'hey do you know what, every sound that I hear is processed by computers first. Like everything' and they're like 'oh wow that's cool'"* (P1, MU4).

4.1.4 The Impact of HL on Personal Relationships. Small misunderstandings with regards to hearing loss could impact people's relationships, such as the appearance of rudely ignoring someone when they had not heard them. This happened to P2 with work colleagues in his office:

“Somebody comes up behind me and starts talking to me and [...] it looks like I’m ignoring them” (P2, CI).

However, ongoing interactions with close personal contacts facilitated *“learning [...] how to be a person that can actually be much more helpful when someone has hearing loss” (P5, MU1)*. However, participants mentioned how their hearing loss can sometimes add an extra level of strain when arguing with a significant other: *“They’re having to repeat stuff as well, which is annoying anyway, which just kind of adds extra annoyance” (P2, CI).*

For P3 who experienced hearing loss in adulthood, family get-togethers provided a frustrating situation where she was unable to engage in the way that she used to: *“they all [...] talk over each other, and nobody will make any adjustment for me, so I just can’t go” (P3, CI)*. Her mother continued to talk in unsuitable ways for HL, and this communication breakdown damaged the relationship: *“Our relationship’s pretty much ended because she’s just never gonna make any effort to speak to me in a way that I can hear” (P3, MU2).*

4.1.5 Summary of Social Impacts of HL. In line with hearing loss research, we found that social factors impacted how participants perceived their hearing loss AT. Beyond the *“hearing aid effect”* [19], our research showed the impact of communication breakdowns that ranged from awkwardness to fundamental changes in relationships. Positively, these breakdowns can inspire individuals without hearing loss to learn about how they can better communicate with the participants with HL. There are parallels to other assistive technology research where there are arguments towards shifting accessibility towards inclusion [46], which links to supporting communication between people with and without HL. These one-to-one, social frustrations impacted participants’ quality of life and influenced their motivation to hack hearing.

4.2 Using Hearing Loss Technologies in Everyday Life

This research also revealed that beyond social factors, there were wider cultural and societal impacts influencing participants’ use of HL AT. Within the technology design domain, culture has been defined as *“a socially shared symbolic system of signs and meanings”* [5]. Culture in this sense is about framing experiences to *“bring structure and meaning to them”* [43], and this is linked to *“real, practical effects”* on technology use [30].

4.2.1 Hearing Loss Compared to Other Impairments. Participants mentioned how many of the misconceptions about HL stem from how people attempt to understand it by comparing it to visual impairments. This could be due to how common visual impairments are [62] and more easily simulated than partial hearing impairments: *“You can just close your eyes and see what it feels like not to see [...] but you cannot shut your hearing, so yeah you don’t know what it feels like not to hear” (P6, MU1)*. Visual issues often can be accommodated with the use of glasses, contacts, or surgery. This mental model of having an AT solution to an impairment falsely carried over to HL: *“[sarcastically] you put hearing aids in, it’s like putting glasses on, and then you can see again” (P5, MU2)*. A lack of understanding at a wider societal level was a constant source of frustration: *“It would be amazing if I could say to someone ‘I’m hard of hearing,’ and they’d know what to do” (P3, CI).*

4.2.2 Physical Context and Cultural Impacts. Not only is there a perceived mistreatment at a societal level, but participants also mentioned an absence of sensitivity at a smaller cultural scale. Participants mentioned a lack of accommodation for HL in modern workplaces, as there is a trend towards open plan offices. When such spaces are populated by many people, an overwhelming sound level is created: *“you’ve got sales guys over there and these guys are having a stand-up meeting over here” (P2, MU2)*. These offices thus do not accommodate HL, which impacts work experience and even the choice of workplace: *“a hundred people in a massive warehouse and, just music all the time [...] I’m not going to stay there very long” (P1, MU2).*

The most common strategy was to avoid physical contexts that *“are reflecting the sound so that creates a lot of reverberation” (P1, CI)*. However, this could lead to fundamental changes in the way people interacted with others, such as becoming *“introverted” (P3, MU4)*. For one participant, the number of *“places where there would be background noise”* that he avoided led to isolation and *“shrinking back from society really” (P9, MU2)*. It was not uncommon for participants not to engage in activities they could potentially enjoy or used to enjoy: *“No more groups, no more parties, no more socialising, no more restaurants, no more bars, erm... travelling, I don’t know if I’ll ever be able to do things like that” (P3, MU2)*

4.2.3 Hearing Loss and its Association with Frailty. Much research has focused on stigma and AT devices [45,58,66], including HL AT [21,25]. Participants also mentioned a specific stigmatizing cultural factor: hearing loss technologies being associated with frailer, older people:

“like picking up a walking stick” (P2, MU1). This cultural stigma is linked to the design of the devices: *“Even just 10 years ago, the first hearing aids I was prescribed were big fat grandpa ones and I just freaked out.”* (P12, MU4). Such associations with older adults contributed to participants’ concern for *“what people think”* (P6, MU1), when people noticed the use of hearing technologies and how these societal perceptions might impact their lives: *“It’s my company, my business and I got people working for me, I felt really like sad to say but if I started to look weaker, you know, something like this”* (P13, MU4). Participants suggested that such reactions to the stigma of looking “weak” while using hearing technologies influenced non-use and hiding HL.

4.2.4 Hiding and Showing Off Hearing Loss. Although the reasons for hiding and showing off HL technology are particular to HL, these findings have parallels to research on hiding and showing off mobile medical devices based on the context in which they are used [55]. People with HL were conscious of visibly wearing hearing aids and some hid them with hairstyles [22]: *“You cut your hair, you, you start going around like ‘oh man what are people going to think of me now’”* (P1, MU1). One participant described an encounter with someone who thought hearing loss should be hidden permanently behind hair: *“The guy who was wearing [a hearing aid] actually said [...] you need to grow your hair longer (laughter), just hide the hearing aid”* (P6, MU1). Hiding hearing aids and other assistive technology could mean that the participants were avoiding some of the cultural frustrations that arose because of their hearing loss: *“what I did was I hid them because I felt insecure about them”* (P8, MU1).

In contrast, there is an emerging culture of showing off one’s condition [54,61], including HL. A speech therapist discussed her experience in Canada where children are encouraged to show off ATs: *“they always have the colours and the stickers and things”* (P4, MU1). Aesthetics are important [61], and some participants chose to buy hearing aids based on how they looked, even though they could have bought hearing aids that were more subtle: *“I thought, you know, why not make it fashionable”* (P6, MU1). The open use of HL technologies can depend on style. For instance, P13 mentioned how his son had a preference for one hearing aid over another: *“no no dad you can’t wear those ones [...] because you look like an idiot [...] when I tried these ones he said [...] ‘you’re cool now daddy’”* (P13, MU4). The use of visible hearing technologies also had a practical purpose. Some participants mentioned that their hearing AT should be

seen because it can act as a *“visual reminder”* (P5, CI) of HL for communicative reasons, and not something to hide away.

There are other trends that are influencing the culture of showing off hearing technology: the availability of consumer technologies that are worn on the ear, such as Bluetooth headphones. Participants discussed how advances in these commercially available products decreased the stigma around wearing AT in one’s ear, such as headphones *“that are meant to be seen, they’re a fashion statement [...] exciting because then the stigma of wearing a device on your ear and it should be really gone”* (P5, CI).

4.2.5 Inadequacy of Peer Support for Hearing Loss. Although support groups are common for some conditions, hearing loss support groups are not, and so participants are unable to access *“the AA feeling”* (P13, MU4) of having peers to regularly engage with. MU4 attendees discussed the inadequacy of the wider peer system supporting HL: *“You need a lot of other things [...] Like even group support like this [agreement noises]”* (P1, MU4). The meet-ups began because of the lack of a peer support network - even in a city the size of London - spurred a group of people to start one: *“There’s not so much around hearing loss, in terms of you know, knowledge or groups or like, so I thought it would be a good idea to start one”* (P1, MU2). Participants expressed a desire to meet others with HL to find a supportive community who could understand what they were going through and could provide support and inspiration to not be hindered by their impairment: *“You feel okay, I’m not alone, they can do it, I can do it”* (P13, MU4). In MU4, the group expressed a desire to engage with inspirational people with hearing loss who could give talks and share *“‘I’m happy where I am, and you can do exactly the same’”* (P13, MU4).

4.2.6 Summary of Everyday Impacts on the Use of HL AT. Overall, cultural factors such as a general lack of understanding and public accommodation of HL, and the stigma surrounding hearing loss impacted participants’ use of HL technologies. Importantly, it also impacts everyday lived experiences. These cultural influences lead participants to either adhere to the culture of hiding their hearing loss or resolve to be a part of an emerging culture of showing off their hearing loss. The need for a system of peer support is also clear. These findings show broader public and societal changes need to address the root of these stigmas and potential mistreatments. However, it is evident that the participants thought the personal design

and development of hearing loss technologies could be part of that cultural shift.

4.3 Systematic and Industry Impacts on Hearing Tech Use

Participants were frustrated with the HL industry, and this impacted their use and experience of related AT. The frustrations were directed at medical, manufacturing, marketing, and consumer HL AT sectors of the industry.

4.3.1 Frustrations with Diagnosis and Hearing Tech Support. Hearing loss is often measured by testing whether someone can hear sounds at particular tones and pitches: *“when they play a sound doooo... then when I hear it in this ear all I hear is bzzzzz”* (P3, MU2). Participants mentioned feeling frustrated with how the tests only measured if they were heard but not how they perceived the sounds: *“they don’t pick up the fact that it’s got no pitch, no tone or no definition [...] so, something is wrong in the actual testing”* (P3, MU2).

Additionally, participants mentioned that a major flaw of hearing tests was that they were performed in *“totally artificial”* (P4, MU4) sound proof rooms, a problem that motivated other research on a tangible sound interface to replicate contextual sounds [17]. Participants described the testing room as unrepresentative of the types of environments that they experience day-to-day, and wanted the power to adjust their HL devices in-situ instead of attending multiple readjustment sessions: *“I had to go backwards and forwards [...] for months [...] they have to adjust to your hearing, but who better to adjust than us”* (P3, CI). Participants were frustrated by their stunted freedom of choice of HL AT due to the necessity of an audiogram: *“You’re not necessarily given an audiogram, an audiogram is what you need to be free to choose whatever product you want”* (P1, MU1).

The lack of general support and services available that might improve experiences with HL technologies was mentioned, similar to issues people experience in the hearing aid fitting and use *“journey”* [70]. P5’s grandmother chose to use the public National Health Service (NHS) hearing aids that she had previously found *“so unbearable”* (P3, MU2) because she was not given enough information about the new hearing aids from a private provider that could have given her choice and support in using them: *“certainly none of that sort of aftercare support”* (P5, CI). Although participants expressed frustrations with a lack of support, they also suggested *“most audiologists don’t have the time”* (P1, MU4).

4.3.2 Frustrations with Design, Manufacturing and Marketing. Participants were frustrated by what they perceived to be underperforming hearing aids. Other than conversing, the underperformance of HL AT also influenced more subtle elements of participants’ lives, such as sports and physical exercise. Trying and failing to communicate quickly during team sports using hearing aids was described as a *“frustrating thing”* (P1, MU2) and playing squash was hindered because some hearing aids are not waterproof: *“Yeah, it’s definitely sweat”* (P1, MU2). Participants mentioned how HL device manufacturers were not working on providing the useful features that hearing technology users believed were missing, which has parallels to Mol’s observations about diabetes device advertisements selling lifestyles that were not in line with actual wants and needs [48]. Participants suggested that instead, manufacturers had a misguided focus: *“making them smaller [...] they could be a little bit bigger and still be comfortable”* (P3, CI). Participants felt frustrated with this industry obsession: *“the problem is that when they’re big, they’re ugly, it’s not the fact that you can see [them]”* (P1, MU2). Participants mentioned that the culture of hiding HL was reinforced by how hearing aids were advertised as *“tiny”* [33], leading to a cycle of reinforcement that perpetuates the ‘invisible’ myth: *“‘nobody will notice you have hearing aids’, this enforces the message that it’s a shame to wear hearing aids”* (P1, MU1).

Beyond frustrations with the design and advertising, participants felt it was *“a shame things are moving so slowly in that field”* (P2, CI) with slow release cycles: *“they’ve been in our ears for the last sort of 30, 40 years [...] there’s no innovation there”* (P5, CI). Views on the slow pace of manufacturers were similar to the diabetes community’s #WeAreNotWaiting movement who are designing and developing their own solutions [52]. This perception stemmed from comparisons of *“expensive” “clunky medical devices”* for HL with consumer electronics such as *“noise cancelling headphones”* (P2, CI) with superior functionality.

Participants believed that these design and accessibility issues resulted from a lack of engagement with the end users of these devices. Participants discussed wanting to reach out manufacturers to *“berate”* them but also provide user input: *“through groups like this, I think the more they become aware that there is a market”* (P12, MU4).

In addition to lack of user input, participants also found it difficult to find out about new innovations that have been released: *“clinics don’t really have sort of er, tech newsletter or something”* (P1, MU2). Participants thought

this was the fault of the marketing departments not sufficiently explaining the HL devices they were trying to sell: “it just doesn’t seem like they’re very good at letting people know about this stuff” (P3, MU2). A lack of clarity about the products was mentioned as a reason to distrust companies, ultimately influencing how the participants chose their devices: “four different models [...] they look exactly the same [...] there’s no clear explanation of the differences [...] and my suspicion is that there’s no difference at all” (P1, MU2). Lastly, when there was any marketing or promotion of products, participants could find them dissatisfying or slightly offensive: “[the marketing] looks so old and outdated... it frustrates me because it’s tailored for my grandmother” (P5, CI). This could contribute to perpetuating the stigma surrounding the use of hearing AT [60,71].

4.3.3 Summary of Systematic Impacts. Overall, the frustrations that participants had with the hearing loss industry concerned the diagnosis and treatment from the medical sector, the functionality of the hearing aids from the manufacturing sector, the problems from the hearing aid marketing sector, and the reduced accessibility from the consumer hearing technology sector. This lack of connection between the design and deployment of HL systems and the lived experience of people with HL impacted participant engagement and experience. Moreover, it impacted the quality of their lives. Similarities between these medical and manufacturing frustrations and those of the #WeAreNotWaiting DIY diabetes communities are apparent [53], and along with the social and cultural frustrations presented above, influenced participants to start and attend these meet-ups. Furthermore, it ultimately influenced the

development of personal solutions to these frustrations.

5 ADOPTING, ADAPTING & HACKING HEARING LOSS

The participants engaged in innovative solutions to their hearing loss, which is at odds with some research on hearing aid users engaging fewer coping strategies and being “less imaginative in coming up with novel approaches” [15]. Maestri and Wakkary [42] believe everyone is a designer and design is an ongoing activity that includes repair, modification, and the appropriation of design objects and systems. This was a phenomenon observed in our participants, as they designed numerous solutions and applied strategies, similar to resilience strategies, to avoid difficult HL situations [23]. The social and societal frustrations outlined above led to DIY practices of adoption, adaption, and the design/development of bespoke solutions.

5.1 Adopting AT and Other Useful Solutions

Some non-digital solutions were used and shared at the meet-ups, particularly to deal with physical places that were not conducive to people with hearing loss at work and school. One method shared was to use soft textiles and surfaces, such as a “sleeping bag in the corner of the room,” (P4, MU2) to reduce the amount of reverberation. P1 shared a more permanent fabric installation solution to high ceilings in an open office: “so, we got some panels in there and everything instantly turns so much better” (P1, MU2).

A more common adoption method was buying and using available HL technologies to lessen the personal impact of hearing loss: “I work full-time so I depend on

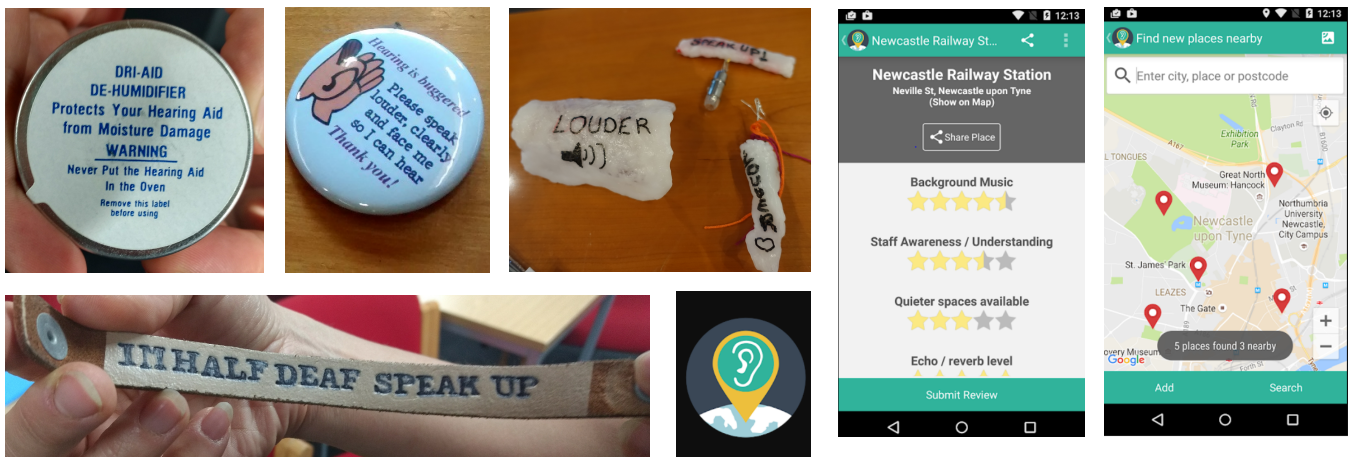


Figure 1a) Hearing Aid Dehumidifier, b) HL Badge, c) HL LED Jewelry Prototypes, d) Bespoke HL Bracelet, e) HearAdvisor Branding, f) HearAdvisor Ratings, g) HearAdvisor Map

technology to try and be normal and keep up with everything” (P12, MU2). Some devices that can be bought to improve hearing experiences, including the Roger Pen, allow the user to clearly hear the voice of an individual: “I can point it at someone and hear them speak, which is amazing, in a room full of people” (P3, CI). However, these assistive technologies were not covered by the NHS and were expensive “so if you can’t find that money [...] you then don’t get the help you need from the technology [...] needs to be more accessible to everyone” (P3, CI). Financial situations have been found to impact HL AT adoption [44]. However, there are less expensive accessories can also be bought for hearing aids that were shared in the group, such as a tool that collects moisture, like sweat from doing sports: “it blows the air and it dries them out” (P4, MU2) (Figure 1a).

5.2 Adapting and Appropriating Solutions to Hearing Loss

Beyond adopting new devices and accessories, other systems were appropriated and adapted for HL to improve the lives of the participants. This included information resources, such as websites and blog posts not originally meant for hearing loss. These were shared at the meet-ups as a way to identify places that were good for people with hearing loss to meet and be able to hear others in: “A blog called ‘A Peace of London’ [...] some deaf and hard of hearing places to go” (P3, MU2). An appropriated non-HL device used was Live Scribe, which audio recorded conversations in a digital pen. P11 shared how he was able to revisit what was said in work meetings by writing notes in a special notebook and tapping a word to “go back to” (P11, MU4) parts of a conversation that might have been missed.

Adaption also occurred in terms of a shift in communication technologies to include more text-based mediums (such as email) so that participants did not then need to focus or rely on hearing, thereby getting tired or missing out on conversations. Although face-to-face communication is necessary in some situations, participants also described circumstances where social media was better: “exchanging information, or giving up dates or whatever, then I prefer to just have that in a chatroom, something like slack.com, or trello or something” (P2, CI). Participants sometimes chose to suggest text-based mediums of communication, even if it meant exposing their hearing loss in a professional setting: “If it’s a work thing, then actually I really need to expose myself and say ‘no, sorry, I really didn’t hear that, so I’m not gonna

hear you in here, you’re just gonna have to put it in an email. Write it down for me!” (P12, MU4).

Some adaptations and work-arounds were used for underperforming hearing aids, but not without consequence: “Just crank up my technology so loud that it would be like overwhelming but I’d hear them, and I’d be able to engage but I’d get tired really quickly” (P12, MU4). Some found that the easiest solution to their frustrations was just to temporarily stop using their hearing aids in some situations: “it’s sometimes easier just to take the hearing aids out or switch them off or whatever” (P2, MU2).

5.3 Creating, Developing and Hacking Hearing Loss

Beyond adopting and adapting technologies to aid communication, participants described creating, or wanting to create, tools and technologies that better suited problems that they were personally experiencing. One participant has mentioned writing and launching a course designed to offer help, tips and tricks that they found to be personally useful to people with hearing loss in order to overcome frustrations around communication: “I basically created a hearing rehabilitation course online” (P1, MU4).

Some participants started collecting lists of places to go for personal use: “I do have some places, erm, a mental list and I also have a written list I can work around” (P1, CI). For example, the lack of efficient accommodation for HL at specific locations such as cinemas was something participants wanted to share: “They give us half price tickets but we can’t go because we can’t hear what’s happening [...] and they’ll say ‘oh, we have subtitles showing’ but they’re like Tuesday afternoon, who goes cinema Tuesday afternoon?” (P3, CI). One idea that was brought up during MU2 was to have a resource similar to TripAdvisor that could allow the hard of hearing to see which locations could best accommodate HL: “I wanted to set [...] up like some kind of rating system, so if they achieve gold star and they have all that [...] like there’s one Pizza Express in the country which gives you a portable T-loop, and so then they would be gold star” (P3, MU2). This idea ended up being developed into an app, HearAdvisor (see Figure 1g), in the third meet-up using the online community platform App Movement [24]. The participants came up with the name, branding (see Figure 1e), and the criteria for assessment for how accommodating a place was for people that have hearing loss. (see Figure 1f). The criteria (Background Music, Staff Awareness/Understanding, Quieter Spaces Available, and Echo/Reverb Level) were based on the frustrations they shared, discussed and experienced with hearing loss in

establishments and public spaces. It is currently available for download (Apple and Android) at the time of writing.

Other solutions designed and developed included personal, worn communication aids (Figure 1d). These were to increase awareness for one-to-one conversations: *"I made these badges which I now sell [...] 'Hearing is Bugged', 'Please Speak Really Loudly' usually people go, 'oh sorry' and then they speak louder"*(P3, MU2) (see Figure 1b). Participants had numerous ideas for future DIY products to bring about awareness to their hearing loss through bespoke HL accessories. The prototype examples in Figure 1c have LED lights in them that they would be able to turn on to remind people to speak up mid-conversation, without having to interrupt them and ruin the flow of conversation. The participants even described more drastic measures, such as body augmentation: *"Some kind of piercing [...] if people recognise that you have [...] hearing loss [...] it would help you remind people to speak up"* (P2, MU2).

Participants were also interested in branching out to collaborate on digital and more technical hacks, based on their frustrations with what manufacturers were currently offering as HL AT. One participant was attending the meet-ups with the express purpose of trying to contribute to high fidelity hacking [51] of hearing loss technologies, *"on the software side, so feeling I could maybe contribute to the community in that way"* (P2, CI). In comparison, there were lower fidelity hacks suggested, but they were still motivated by the underperformance of HL AT: *"Much simpler hacks, I'm looking with my brother to create a waterproof like kind of sleeve"* (P1, MU4).

5.4 Summary of Hacking Hearing Loss

Frustrations with hearing loss and hearing loss technologies helped fuel the desire to start a meet-up group, but also to create DIY solutions to problems and share them. Although the problems were often common, through the interviews, meet-ups and the collaborations that were observed, different sets of technologies and artefacts were engaged with in order to create personal bespoke solutions, which is not unlike some of the research on DIY health technologies [52,56].

6 DISCUSSION

Our study has provided insight into the attitudes towards assistive technologies of participants with hearing loss and participants who are connected to the impairment, bringing into focus issues related to these interactive devices that drove DIY design. By engaging with a community that formed to face these issues head-on using

peer support and sharing DIY aspirations, we uncovered sociocultural impacts of HL, technological and systematic frustrations, and some of the emerging bespoke solutions being adopted, adapted and created to address these frustrations.

There are also similarities to other studies of assistive technologies unrelated to hearing loss, such as the social impacts of using AT [20] for the care of health conditions such as diabetes and asthma [32,38]. While there are obvious benefits of using AT, hearing loss devices can have less-than-ideal associations with frailty or with visual impairment aids such as glasses, which can cause social and cultural frustrations that ultimately affect their use and user experience. Like other research, we also found that stigma can lead users to modify, hide or abandon their AT [55,60]. Our results build on these studies by highlighting nuances in the frustrations that stem from a lack of public knowledge and a seeming imbalance in the acceptability of visual impairments over hearing impairments from a cultural lens. From a social lens, these frustrations stem from the impact on the quality and flow of conversations, and therefore the ability to communicate which can strain personal relationships. Although other studies have identified dissatisfaction with aspects of hearing loss technologies such as the appearance of hearing aids [61], we also uncovered deeper frustrations about the hearing loss industry, including the manufacturing, medical, marketing and consumer hearing technology sectors, that drove DIY innovation.

Unlike other studies of assistive devices and healthcare technologies which focus on design implications, our observations of the start of a meet-up group motivated by hacking hearing loss allowed for insight into the solutions people were already employing and wanting to employ to deal with personal frustrations. The findings have revealed the bespoke and individual solutions that participants have created to deal with or solve their personal frustrations. Solutions ranged from tips and tricks to deal with reverb in places such as work, to technological solutions for identifying locations that supported people with hearing loss through the development of a review/map-based app.

This orientation towards inclusion in everyday locations and situations rather than accessibility has parallels to research on social inclusion of people with visual impairments [46]. Rather than assistive technologies that focus on the impairment that are developed by manufacturers, the participants were coming up with solutions that would allow them to

engage with the people without hearing loss, such as the unobtrusive light up badge that would communicate to someone to speak up without rudely interrupting them and breaking the flow of conversation. However, even similar solutions to common frustrations had idiosyncratic aspects, for instance the different designs of the badge, bracelet or earring. This is in line with research that shows the need for bespoke technological solutions to health and care issues [35,54,57,68], and indeed research capturing the trends towards DIY health and wellbeing [38,52,56].

Presenting ‘implications for design’ would not be an appropriate response after engaging with this group and observing some of the personal design solutions they developed to frustrations around hearing loss and AT. These participants are taking on the role of designer [42] and their design requirements are bespoke and personal. Instead, we present implications for researchers engaging with communities creating their own health and wellbeing, and medical and manufacturing sectors of the HL industry.

Researchers can play a role in supporting communities developing grass roots solutions to health, wellbeing and care. Participants expressed their frustrations with the lack of help provided to support their impairment, including peer support. This led to the creation of the hearing loss meet-up group in which participants could provide each other with advice and support, as well as share tips, tricks, and hacks. While the idea for starting a hearing loss support group may not be rare, the difficulties surrounding finding appropriate and convenient venues may hinder attempts at forming such communities. Practical support could be made available for individuals who want to start a support group in terms of providing resources for such meet-ups to occur without engaging in the running of the meetings themselves, including providing appropriate venues and making attempts to improve the acoustic properties of existing ones. A further direction for researchers might be the development of frameworks to support communities in forming around an issue of concern. Work on grass roots, bottom-up frameworks is starting to emerge in areas such as smart city sensing (e.g.[4]), but not yet within the area of DIY health. Practical support could foster the development of communities engaged in hacking and making for bespoke health and wellbeing.

In terms of the healthcare provision, we identified a need for more user agency in the diagnosis and updating of hearing ATs. Participants expressed their frustrations with how adjusting their hearing AT took much trial and

error before they reached comfortable levels, and how the diagnostic process itself involved testing in soundproof rooms that do not reflect natural environments. An important implication would be that audiology could incorporate the perspectives of those with hearing loss to focus on functional hearing in real world environments. Specifically, audiologists or hearing professionals would not be the only ones to solely determine how hearing AT are prescribed or adjusted, but would instead work as collaborators with people with HL in diagnosing and updating hearing ATs. This could be achieved through the design of more effective diagnostic devices with the input of people with hearing loss, or the development of end user customisation for HL AT.

As for manufacturers, there are implications for future design and development of hearing technologies. Participants expressed their frustrations with the mono-functional, slow development of hearing technologies from manufacturers that are “*obsessed*” with making hearing AT smaller instead of engaging with real world user needs. In the future, manufacturers could work alongside hearing communities in designing novel hearing ATs, taking input and ideas that are generated from within hearing communities instead of looking for input after a device has been developed. For example, collaboration with and support for meet-up groups and hackathons could be an important mechanism through which the industry could engage with the challenges faced by those with hearing loss. This could also lead to innovative new technologies. HL AT users understand best what features are missing, thereby offering ideas for the design and development of bespoke, useful, and usable HL AT.

7 CONCLUSION

While hearing loss assistive technologies can make it easier to facilitate communication between the hearing and the hard of hearing, sociocultural factors and technological frustrations may impede the use of the devices. An orientation towards designing AT for inclusion rather than AT for accessibility was shown as a priority for those with hearing loss inclined to develop their own solutions to personal frustrations. As a study of attitudes and perceptions of living with hearing loss technologies, this paper offers evidence about how hearing loss does not have one solution, and that hearing assistive technology users are developing their own solutions to fill in the gaps left by medical providers and the slow development of devices by manufacturers.

Researchers can provide practical support in the development of communities engaging with DIY assistive technology practices, and through engagement with these communities, the medical and manufacturing sectors can facilitate the development of bespoke, useful and usable HL solutions.

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